

Ethical Issues and Navigating Institutional Review Boards

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CHAPTER OVERVIEW

The aim of this chapter is to assist you with recognizing unique ethical considerations for photovoice and with planning accordingly for the application to the Institutional Review Board (IRB) at your institution. Photovoice can be a unique experience for researchers and participants and as noted in Chapter 1, photovoice has the potential to empower participants. However, along with that potential, there are distinct ethical considerations to recognize when using the photovoice method. These considerations are always important but may be even more so if you are using photovoice with marginalized, traditionally underrepresented, or oppressed populations. This chapter will discuss key ethical considerations from our experiences implementing photovoice studies as well as those noted previously by other researchers using photovoice from multiple disciplines. Simultaneously, we offer potential tips for addressing the ethical concerns that may assist with navigating IRB approval of studies using photovoice. Finally, we close this chapter with a case study illustrating our experience with navigating one IRB.

IRB EXPLAINED

A deep dive into all of the nuances of IRBs is beyond the scope of this book, but it is important to have a basic understanding of what an IRB is and how it works. An IRB is an administrative committee within your college or university that is established for the purpose of

reviewing all research to ensure human subjects are protected and that the research methods are ethical. Most photovoice projects need to be approved by an IRB because the overarching intent is usually to share the results broadly beyond the classroom for advocacy. You will need to submit an application and wait for official approval from the IRB before starting your photovoice research. There are often modifications requested by the IRB, so it is best to plan ahead and submit the IRB application at least 6 months prior to the date you hope to start implementing your project. The forms, committee composition, timeline, and general processes vary a lot from institution to institution, so your first step is to investigate the process and requirements at your college or university. Most colleges and universities offer IRB materials online.

We advise students to seek guidance and mentorship from a faculty member with IRB experience if you are new to the process. Sometimes, the IRB may require a faculty member to serve as an investigator on your application, so it is best to determine whether your institution requires this and plan accordingly. There are different levels of review ranging from an expedited review involving only one or two reviewers and less time to a full board review involving all members of the committee meeting to discuss your proposal. Some populations, such as minor children under age 18, pregnant women, and people in prison, automatically lead to a full board review, so again, it is best to investigate the expectations and timelines at your institution to guide your planning process.

ETHICAL CONSIDERATIONS WITH PHOTOVOICE

Photovoice projects are often designed with social justice in mind as an outcome and a desire to tip the balance of power for marginalized populations, people who often have less of a voice due to structural inequities in society. Therefore, it is critical to recognize that the researcher or research team leading a photovoice project has the ethical responsibility for ensuring autonomy throughout the duration of the project. Simply defined, autonomy in research means that a participant makes their own decisions about what they will and will not agree to related to

participation in a research study (Owonikoko, 2013). Additional ethical considerations for implementing photovoice covered in this chapter are informed consent, safety and privacy of co-researchers, the safety and privacy of people captured in photographs, and incentives and payments for participants. One critical point is that even though an IRB may approve your study, there is still an array of additional ethical considerations for you to acknowledge and potentially put into practice due to the nature of photovoice as a CBPR method aiming to reduce the inherent power imbalances present in most research.

CONSIDERATION FOR SPECIAL POPULATIONS

It is important to consider for a moment the use of photovoice in special populations such as people with different physical abilities, who are homeless, youth, or people with different developmental abilities. At first glance, photovoice seems to be a method limited to those who have the physical and intellectual ability to take pictures, meet in physical groups to discuss, and make decisions around how to best use the photos for social change. In fact, the beauty of a method like photovoice is that it is inherently adaptable and flexible enough to be tailored to fit any populations' needs, reading level, language ability, physical ability, geographic location, etc. Indeed, photovoice studies have been done within a spectrum of populations at differing levels of ability, such as people who are homeless (Seitz & Strack, 2016) and persons with physical disabilities (Dassah, Aldersey, & Norman, 2017). In all cases, you, as the project leader, can adapt photovoice to cater to the specific levels of capacity to ensure successful projects. For example, adaptations might include having someone else take photos for people who were physically unable to (LaDonna, Ghavanini, & Venance, 2015) or reducing, lengthening, or having one–one meetings about the photos taken (Bukowski & Buetow, 2011; Hodgetts, Radley, Chamberlain, & Hodgetts, 2007), recruiting through agencies that directly work with and serve these populations (Bredesen & Stevens, 2013), or selecting types of cameras that can accommodate physical disabilities (Greer, Hermanns, & Cooper, 2015).

The takeaway message here, one that we reiterate throughout this book, is that every photovoice project will be different and can be

adapted to what will best serve the population of focus, the abilities and availabilities of the co-researchers, the research topic being explored, and the time and resources available to the research team. In sum, photovoice researchers do what needs to be done in order to facilitate a successful project leading to social change.

Informed Consent in Photovoice

There are different ways to ensure the autonomy of your participants in photovoice. The first, which is also required by all IRBs, is to design an informed consent process that is simple and clear. This includes directly stating the purpose of the project, benefits for participants or lack thereof, potential risks to participants, and that it is entirely their choice to participate in the project. This sounds deceptively simple. One challenge may be balancing your IRB's requirements for written elements for informed consent with the desire to have simple language that will resonate with your participants. Sometimes, IRBs may require certain language in the informed consent form or process that leads to a lengthy document filled with technical jargon that may be above the reading level of your participants. If that occurs, then one suggestion is to advocate for your participants and negotiate a compromise that is acceptable for both you and the IRB. For example, you may be required to include all of the specific statements from the IRB in the informed consent form, but perhaps you can request to edit them to a simpler language that fits a reading level more closely aligned with the population with whom you are conducting your project.

With the informed consent process, another possibility may be to request IRB approval to conduct an oral informed consent as opposed to written if this seems like the best fit for the participants (Gordon, 2000). Another important way to promote autonomy for your participants is to engage in ongoing informed consent through the implementation of the entire project, which views informed consent as a dynamic process as opposed to a one-time occurrence at the beginning of a study (Kadam, 2017). Ongoing informed consent usually does not involve gathering signatures or official consent in the same way as the initial informed consent. Instead, you simply build a process into every photovoice session or meeting with participants in which you start out by reminding them that participation is optional and that they may decide not to participate in the project at any time that day or during

the future. A sample of an informed consent form for photovoice is included in the Tools at the end of this chapter.

Safety of Participants

Safety is an important issue inherent to photovoice that you need to consider and build into both study implementation and the IRB application. In this context, safety should be considered broadly and comprehensively to include physical, psychological, and emotional safety. For some populations, it may be beneficial for the research team to have understanding and training in how to utilize a trauma-informed approach (Harris & Fallot, 2001).

One unlikely, but potential, risk to participants is from people who observe the photovoice study co-researchers taking photos, are uncertain what they are doing, feel threatened, and react with verbal or physical harm. A common way to address this is to dedicate at least one session to “Ethics and Safety” during your photovoice project that occurs prior to the study participants going out to take photos. Organization and approaches to this session vary widely, but the overarching goal is to explicitly address all ethical and potential safety concerns for the participants themselves in the context of the specific photovoice project and to detail concrete action steps that participants can take to protect their safety.

Our approach to ensure the safety of participants is to communicate unequivocally that their safety is an absolute top priority and there is not any photo or portion of the photovoice project that is more important than safety. For example, they may be in a situation where they see an opportunity to take a photo that they feel is an excellent representation of the aims of the project, but it involves community members engaging in illegal activities. In that case, we let participants know that taking the photo is not worth the risk. Another way we have handled this is to use guest speakers from the community who are familiar and respected by the participants. For example, for a project in a school with youth under 18, we invited a school resource/law enforcement officer who reiterated messages about safety and spoke frankly about specific risks to avoid during photovoice in that community. The approach will vary widely, but the key is to have a comprehensive plan to minimize

safety risks in your photovoice project and to be prepared to provide details of your plan to the IRB.

Privacy of Research Participants

Protecting the privacy of people who participate in a research study is an ethical obligation for all researchers. It is important for you, as the person in charge of the photovoice study, to honestly communicate the risks to privacy with participation in a photovoice project. The nature of photovoice is such that it is nearly impossible for a participant to remain anonymous. For example, participants may end up taking “selfies,” which means their face is in the photo. Even if the participants do not end up physically in the photographs that they take, their photos will often have identifiers such as parts of their home, school, community, or property that might allow someone looking at the photo to guess who they are. This may be of high concern for uniquely vulnerable populations needing anonymity such as those experiencing domestic violence, so it is certainly something to intentionally plan and address depending on the privacy needs of the specific population with whom you are working.

An additional area of privacy unique to photovoice is the protection of the privacy of people who are in the photos taken by the participants/co-researchers. There are a few different options that can be used. A common practice is to train participants to use a Photo Release Form, which means the participants talk with the people in their photos to explain the purpose of the project and have them give consent for their image to be shared in the photos by signing a form. There is one example in the Tools section at the end of this chapter. Participants first engage with potential photography subjects before taking their photo, explain the purpose of the study, ask if the person is willing to be in a photo, and obtain their signature. An additional benefit of this approach is that it also mitigates safety risks and enables you to be certain that the photos can be freely used and shared for purposes such as advocacy, presentations, or publications. The potential downsides are that it detracts from spontaneity and some people may refuse to be included. Another variation of this approach is to train participants to implement the Photo Release Form and obtain consent to share the photo *after* the photo has been taken and the participant has identified

that this is an important photo for inclusion in the project and they'd like to share it in group discussions or more widely. A third possibility for protecting privacy of people in the photos of your participants is to have a concrete plan for fully blurring facial features or other identifying characteristics in photos. The benefit of this approach is retaining spontaneity and the ideal to have candid photos, whereas the downside is that the risk for identification of people, even with blurring photos, cannot be eliminated. In sum, there is always a possibility that people will be included in the photos, so the burden is on you as the researcher to have a clear, concrete plan to protect the privacy of people appearing in photographs for research.

Social media such as Facebook, Instagram, or Twitter is yet another area of importance to consider for protecting the privacy of participants. Chapter 6 delves a bit more into social media, but the overarching concern in the context of privacy protection is to make sure that you have an explicit plan for how social media will be handled in relation to your photovoice project. It may be that you decide not to use social media due to privacy concerns. In that case, you would want to communicate that with participants as a ground rule of the project or perhaps put it into writing to ensure that one participant does not violate the privacy of another participant by sharing photos of them or sharing photos that they took during the course of the photovoice project.

Incentives/Payment for Participants as Co-researchers

A final ethical issue to consider is the use of incentives for photovoice participants. Researchers from a wide variety of disciplines use incentives for a variety of reasons when implementing research. However, it is important to recognize that there is a diverse array of opinions about using incentives. One common ethical concern for conducting community-based research in partnership with community-based organizations is the potential for researchers setting an expectation or standard within the community that cannot be maintained by the organization after the researchers have completed the project. For example, one of our studies was conducted in partnership with a refugee resettlement agency that was well known across all groups of refugees in the city (McMorrow & Saksena, 2017; Saksena & McMorrow, 2017). When we proposed to offer photovoice participants financial incentives for

participation in the project, there was reasonable and legitimate concern from the agency that the perception in the community might be that the incentive was coming from them and would be expected for participation in programs they offered. One way to manage this is to ensure that all stakeholders recognize the view of “participants as co-researchers” in photovoice. Then, to communicate that as such, there is an ethical obligation to remunerate them for the substantial time and work involved with attending photovoice training sessions, taking photos, attending photovoice discussion sessions, and potentially advocating for policy change. Yet again, the keys here are to have a definitive plan with a solid rationale and to be prepared to spell out the details in the IRB application. A literature review section of your IRB application that includes examples of prior use of incentives in photovoice may be a good tool to support your request.

NAVIGATING IRBs WITH A PHOTOVOICE STUDY

Navigating the IRB is closely aligned with the aforementioned ethical concerns. This is something that all researchers who work with human subjects need to do before beginning participant recruitment and photovoice is no exception. All photovoice projects will need approval from your university’s IRB before implementation. A sample of the methods section of an IRB proposal is included in the Tools at the end of this chapter for you to get a general sense of the level of detail that is needed. Additionally, if you are working with a community agency, then you will need to find out if they have their own IRB and potentially follow their requirements as well. Students leading photovoice projects are often enabled by their faculty mentors to write the IRB application but usually need a faculty member to serve as the principal investigator for the study. In the same way that no photovoice project is exactly the same as another, IRBs vary vastly from institution to institution. They usually consist of a diverse range of university faculty representatives and often include community representatives as well. In some cases, the leader of an IRB aims to have a diverse representation of faculty who have a firm grasp of both quantitative and qualitative research methodology. In other cases, the IRB may have a disproportionate number of representatives who have limited knowledge of qualitative research

and, sometimes, bias against qualitative methods. Similarly, there can be a diversity of familiarity and value for the photovoice method among potential IRB members reviewing the study.

We have collectively navigated five different IRBs and our experiences range from conducting education and advocacy for the importance of the method with one IRB who was not at all familiar with the method to a straightforward experience of securing approval quickly (Breny & Lombardi, 2017; Madden & Breny, 2016; McMorrow & Saksena, 2017; McMorrow & Smith, 2016; Ruff, Smoyer, & Breny, 2019). The overarching recommendation is to be prepared by thinking through all of the considerations listed in this chapter and accounting for them in your IRB application as well as be prepared to educate IRB members and advocate for the use of the method. It won't always be necessary, but preparation will ensure that you are ready to secure IRB approval and move on to the next step of implementing your study.

CASE ILLUSTRATION: AN IRB EXPERIENCE WITH A PHOTOVOICE PROJECT WITH MINORS

For this particular case, the photovoice study population was Black teenage girls between the ages of 13 and 17 who attended high school in an urban neighborhood with a high crime rate. All research involving minors require that parents give consent for participation in the research study and permission is obtained from the youth themselves, which is called assent. Obtaining assent from youth is an additional factor to consider if you are working with minors and a sample assent form is included in the Tools section at the end of this chapter. An important ethical concern for both the researcher and the IRB was ensuring participants were assenting to participate in the project. Additional considerations were obtaining their parents' informed consent, safety, and privacy of other minors in the school.

The university of the photovoice project researcher was a relatively small school with a historical focus on teaching and a less robust history of diverse research by faculty. Therefore, this necessitated education and advocacy for the photovoice method. For example, the first IRB submission was returned to the researcher with a long list of questions and modifications. The researcher met with the chair of the IRB to

describe the method, advocate for the importance of using it, and seek advice from the chair on how to improve the application to address the particular concerns of that IRB. To address safety explicitly within the context of the environment of the study population, it was agreed that the school resource officer (police officer) would serve as a guest speaker for the photovoice training to focus on risks related to the neighborhood.

In terms of the concern about privacy of other minors in the school, the eventual compromise was that no photos of other people could be included in any public sharing of photos that emerged as data in the study. In retrospect, this is not a compromise that we would advise. Instead, if you find yourself in a similar scenario, we recommend continued advocacy to confirm that privacy could be ensured by blurring of people in photos or obtaining photo consent. One way to do this is to provide recent examples from the literature of other researchers who have utilized similar methods to address ethical concerns when using photovoice.

CONCLUSION

As with any research project, it is critical to build time into the planning of the project to think through the ethical considerations and potential risks to participants. The goal is to prepare for success right up front with concrete plans and backup plans. Photovoice projects introduce an additional layer of ethical concerns, beyond many traditional research approaches, due in part to the nature of the use of photography and the potential for a breach of anonymity. This chapter provided an example of how to navigate IRB boards to ensure protection of both research participants and research team members as well as samples of several tools that might be used. In the next chapter, we turn toward the next phase of getting your photovoice project started with concrete steps and tools to guide you through that process.

Chapter 2 Tools

1. Sample of IRB Application Methods Section for Photovoice Project
2. Sample Photovoice Photo-Release Approval Form: Investigating Social and Environmental Cues for Relationship Power: Photovoice Photo-Release Approval Form
3. Sample Consent Form for Participation in Photovoice Research: Exploring Young Men's Perceptions of Safer Sex Responsibility: Consent Form for Participation in Photovoice Research
4. Sample Youth Assent Form

Sample of IRB Application Methods Section for Photovoice Project

METHODS

There will be two groups: males and females. Participants will attend a total of four group sessions. Initially, they will receive a structured training program consisting of one 2-hour session of experiential skill building. The introductory session will include an Introduction to Photovoice and Principles of Documentary Photography (including ethics, informed consent, and communication skills). Following the initial training, participants will be asked to use their personal cameras or camera phones to take photo assignments.

Participants will be given a workshop on the ethics of camera use by the principal investigator. The ethics orientation will be conducted prior to the signing of informed consent forms. The purpose of this session is to ground participants in the responsibilities, power, ethics, and potential risks of taking pictures in the community. The group discussion in this session will include questions such as: What is an acceptable way to approach someone to take his or her picture? Should someone take pictures of other people without their knowledge? To whom might you wish to give photographs and what might be the implications? When would you not want to have your picture taken? (Wang & Burris, 1997). The youth will be instructed that photographs that do not have photo-release forms signed will not be displayed with the project. In addition, youth will be instructed to not take pictures of any illegal acts or nudity in their community and that any such photographs will be destroyed.

There will be four photo assignments with a follow-up discussion on each one. An initial question for the first photo assignment might be, "For people your age, what do relationships look like or mean?" Participants will then meet every 2 weeks for three additional sessions. At each session, the discussion will focus on the following questions, which comprise the SHOWeD technique: What do you See here?

What is really Happening here? How does this relate to Our lives? Why does this situation, concern, or strength exist? What can we Do about it? Themes will be identified and short descriptive pieces written. Other questions for photo assignments might include:

1. What messages do young girls receive about relationships?
2. How do men gain power in relationships?
3. What messages should be developed and targeted to young women to help them own their power?

Results of the photos and discussions will be structured around (a) identifying the cultural, environmental, and social messages that create an imbalance in power and (b) initiating discussions about gender imbalances and potential solutions.

Release forms will be used by participants when taking pictures of other people (See the following page).

Sample Photovoice Photo-Release Approval Form: Investigating Social and Environmental Cues for Relationship Power

PHOTOVOICE PHOTO-RELEASE APPROVAL FORM

Hi, my name is _____ *<insert your name>* and I am with Southern CT State University. I am involved in a Photovoice research project, where students from Southern are taking photographs of messages in the community that represent gender roles, can perpetuate gender roles in relationships, and also show relationship power. The photographs will be used to create discussions about youth and our community. The project is led by Dr. Jean Breny at Southern Connecticut State University (SCSU).

The photographs I take will be used for research and education purposes only, including use at lectures, conferences, and with published materials. No photographs that identify your family, other individuals, or me will be released without the written consent of those photographed.

I need your approval to use any photographs with you in them. If you agree, I need your signature on this photo-release form.

Please sign here: _____

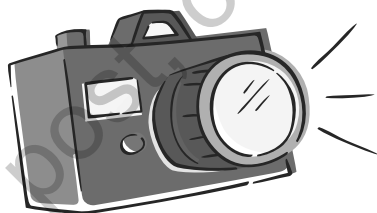
Date: _____

Sample Consent Form for Participation in Photovoice Research: Exploring Young Men's Perceptions of Safer Sex Responsibility

CONSENT FORM FOR PARTICIPATION IN PHOTOVOICE RESEARCH

DR. JEAN M. BRENY, PRINCIPAL INVESTIGATOR

You are being asked to participate in a photovoice project. This project is being conducted as part of a research project on the social, cultural, and environmental factors that influence relationship power in heterosexual relationships. The principal investigator is Dr. Jean Breny in the Department of Public Health at SCSU. Please feel free to call Jean, at 203-XXX-XXXX, if you ever have any questions about this study or your involvement in this study. Alternatively, you can contact the SCSU HRPP at 203-XXX-XXXX. The project is funded through a grant from the Connecticut State University system.



iStockphoto.com/Auki

The purpose of this photovoice project is to provide an in-depth and reflective look at how young people receive messages about gender norms from society and how they are translated into power imbalances in relationships. The research will enable participants to express their experiences through picture taking, dialogue, and conversation.

Your involvement will consist of attending a series of four focus group discussions to process and discuss pictures taken by you and others between these group sessions. With your permission, the group discussions will be tape-recorded for analysis purposes. These tape

recordings will be used to transcribe the focus groups and the transcripts read for themes in the analysis process. Your name, and any other identifying feature, will not appear on the transcript. At each group meeting, you will be given a photo assignment to be completed for the next session. These assignments will be decided upon by the group members and will focus on some aspect of relationship power and decision making. You will attend one introductory session on photovoice and receive your first photo assignment. We will all meet again in 2 weeks, where we will discuss that assignment and give you another one. This will continue until we have had four discussions. You will be given a gift card to the campus bookstore for your involvement in this project. It is expected that the project will be done within 4–5 weeks.

Your participation in this research project is completely voluntary and you can refuse to answer any question or you can leave before the end of the duration of the project. If you decide not to answer some questions or leave, your decision will not affect your relationship with the University or the researcher in any way.

Every effort is being taken to protect your identity. However, there is no guarantee that the information cannot be obtained by legal process or court order. You will not be identified in any report of this study and the only people who will be here today are you, other participants, the researcher, and an assistant. You can choose to use a fake name, and your real name will not be written down anywhere. Each focus group will be taped so that it can be transcribed. You can refuse this or can have the tape turned off at any time. If you agree to be tape-recorded, your name will not be on the transcription and the tape will be destroyed immediately after it has been transcribed. All data will be kept in a locked file cabinet and destroyed after 3 years.

The benefits of participation and talking about your experiences about relationship power will help this researcher, and others, develop relevant and effective STD/HIV prevention programs for people of your age. The only risk to you in participating in this group might be that you feel anxious talking about something personal and the time you spend here may take you away from other activities.

By signing below, you agree to participate in today's focus group.

Signature

Date

Sample Youth Assent Form

Project Title: Saginaw Valley State University Assessment of Barriers and Assets to Healthy Eating Using Photovoice by Youth in Saginaw, MI

Principal Investigator: _____

Community Partners: _____

Participant's Name: _____

In this research project, you and other participants are invited to take pictures and tell stories about the positive and negative influences on healthy eating in your life and community. This is a chance for you to teach others about what affects healthy eating in your life.

If you decide to take part in the project, you will be asked to:

- Take part in training and learn about taking photographs.
- Take pictures of things that influence healthy eating in your life and community.
- Meet with other participants to discuss each other's photographs. As part of the project, some discussion sessions may be audio- or video-taped and notes will be taken. You may also be asked to participate in an interview.

If you agree to participate, you will be assigned a disposable camera for taking pictures during the project. The project staff will develop the film. You will be given a copy of your developed pictures. By signing this consent form, you are agreeing to let the project staff use the photographs you take. Your name will never be used other than during discussions unless you wish to use your name or a pseudo-name.

At any time, you may ask us not to use any specific photograph(s) or story. If you wish to participate in the project and do not want our

photographs or stories used, you may do so. You may also withdraw from the project at any time and there will be no negative consequences.

This research project is being conducted on behalf of Saginaw Valley State University in conjunction with the Saginaw High School Based Health Center operated by Health Delivery, Inc. If you have any questions about this project, you or your parent or guardian may contact Shannon McMorrow, Principal Investigator from Saginaw Valley State University xxx-xxx-xxxx or smcmorro@svsu.edu at any time. You may also contact the Chair, SVSU Human Subjects Institutional Review Board (xxx-xxx-xxxx or irbchair@svsu.edu) if you have any questions or problems that come up during the study.

Remember, your participation is completely voluntary. Signing this paper means that you have read this and that you want to be in the project. This is your decision. You may decline to participate in the project at any time.

This consent document has been approved for use for 1 year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and reference number in the upper right-hand corner. Subjects should not sign this document if the corner does not show a stamped date and reference number.

Print Your Name Here

Date of Birth

Sign Your Name Here

Today's Date